

## New Commission Member

Governor Mike Huckabee appointed Jimmy Ashley to serve as a member of the Arkansas Spinal Cord Commission on December 4, 2001. There are five Commission Members, each serving a ten-year term, who oversee the agency's goals, policies and services.

Jimmy, a native Arkansan, sustained his spinal cord injury from a gunshot wound while he was on duty as a Mississippi County Deputy Sheriff 21 years ago. He and his wife Chris, a Physical Therapist, live in Jonesboro where Jimmy is very active in his community, serving on the HealthSouth Rehabilitation Hospital Advisory Board, a VIP volunteer with the local police department and a member of the Fraternal Order of the Eagle.

He is an active outdoorsman and has acted as a guiding force in the Arkansas Disabled Sportsman Association, organizing over a dozen disabled hunts this season in the state and presently serving as secretary-treasurer of the association. A longtime bowler, Jimmy also serves as Vice Chair of the American Wheelchair Bowling Association.

We hope he will find time to share his experience and expertise as a member of the Commission. Jimmy replaces Russell Patton, III of Jonesboro, the longest serving member of the Commission, whose tenure stretched from 1985 to 2001.

Please join the ASCC Members and staff in welcoming Jimmy to the Commission.



*Jimmy Ashley has been appointed to the Commission by Governor Huckabee.*

## Top 10 New Year Resolutions for Individuals with SCD

The year 2002 is here—a new beginning! This is the time so many of us make our list of resolutions to become better persons. The infamous list of things we know we could do, should do—and from this day forward, are gonna do. Here is a list of resolutions suggested for persons with spinal cord disabilities (SCD).

### To Be Done Daily

1. I will smile hard at least three times a day.

2. I will maintain my body's scheduled need for range of motion and pressure relief.
3. I will eat at least one meal that is nutritious and good for me.

### To Be Done Weekly

4. I will call and check on a friend or family member I haven't heard from in a while.
5. I will take at least one hour of quiet time to pause and reflect.

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## SPINAL COURIER

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## With Thanks

### *Donations this quarter from:*

Conway Physical Therapy Clinic  
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*In Memory of L.J. Prestridge, Jr.*  
Melba Gates  
John & Margie Fraser & family

*In Memory of Marie Sullivan*  
Mr. & Mrs. Herbert H.  
McAdams II

ASCC accepts tax deductible donations. The generosity of the many individuals and families, who over the years have made memorial donations, is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

## SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

### Newport, AR Support Group

Dear Editor:

I am a VISTA Volunteer with the Arkansas Disability Coalition and have formed a new support group in Newport, AR for persons with central nervous system disorders (spinal cord injury, spina bifida, traumatic brain injury, MS, CP, etc.). Meetings are held at **7:00 p.m. on the first Thursday of each month** at Village Creek Apartments Community Room, 1707 McLarty, Newport, AR.

A support group is a great place to share information, ideas and experiences. The meetings are open to individuals with CNS disorders, their family and caregivers. Please join us!

For more information, contact me care of AR Disability Coalition at **1-800-223-1330** (voice/TDD), e-mail: **[rpriidmor@ipa.net](mailto:rpriidmor@ipa.net)**

*Richard Pridmore, VISTA Volunteer  
Arkansas Disability Coalition*

### From the Director

Good...Fast...Cheap...Pick 2! I was listening to Dr. John Banja, a Medical Ethicist at Emory University, speak at a conference I attended. He was talking about ethics and the provision of health care in America. What he said was, it all comes down to those three, and you only get two! At best!

It took a while for the concept to sink in. After all, we live in the most prosperous country in the world—shouldn't we expect good, fast and cheap health care? But, as I thought of it in my own experience, it was true! If I use my HMO it is cheap and usually good, but seldom fast. When I need something fast (and of course, I always want good), it isn't cheap. The same thing likely applies with the services the Commission purchases and provides. We try to get good quality equipment and the best price—and it never seems fast! If it's fast—well, you see what I mean.

So, what was Dr. Banja's message? I kept waiting for him to say "pick two" wasn't ethical—that we are entitled to all three—he didn't! Basically, what he said was that if you have to pick two, make sure you make a good, informed choice! What does that mean? If you want good and cheap, plan ahead; it won't be fast. If you want fast and cheap, be prepared to fight it out to get quality. If you want good and fast, expect to pay more! Simple as that? Sad story to start off the new year? No, just a reality check! Something to think about!

If you would like to make a contribution, please contact the Commission at **501-296-1788 / 800-459-1517** (voice) / **501-296-1794** (TDD), or send your donation to:

**AR Spinal Cord Commission  
1501 N. University, Suite 470  
Little Rock, AR 72207**

Now, if you want good, fast AND cheap, mark your calendar for **May 31, 2002**, the ASCC Conference at the C.A.Vines 4-H Center. It is shaping up to be our best one yet! Hope to see you there!

*Cheryl L. Vines*

# Staff Changes in the ASCC Magnolia Office



*Welcome Felicia Rufus (left) and congratulations to Janet White (right) in Magnolia!*

Janet White has assumed the duties of Case Manager since the retirement of Annie McKnight. Janet has been employed with the Commission since 1987, so her familiarity with the Southwest Arkansas caseload is a definite asset. For many

years clients have been talking with Janet when they call the Magnolia office, and now they will have the opportunity to meet her in person as she begins providing Case Management services.

While working full-time Janet obtained her degree in 1997 from Southern Arkansas University. Her determination and years of persistence can now be channeled into the role of Case Manager. Janet has already begun her quest to meet the individuals in the ten counties she serves.

Felicia Rufus has joined the Magnolia office and will be providing secretarial support to both Janet and Evelyn Wainwright. Her specialized training in Office Systems

Technology from the University of Arkansas Community College at Hope is a welcome asset to the agency. Felicia's enthusiasm and positive attitude are qualities soon to be shared with anyone calling the Magnolia office.

The ASCC staff extends congratulations to Janet on her promotion and a hearty welcome to Felicia!

## Harrison Miniconference



*Edgardo Pineda (center) is very happy to have won the Quickie wheelchair!*

The Telecommunications Access Program (TAP) is a public service telecommunications equipment distribution program established by the Telecommunications Act of 1995 through Arkansas Rehabilitation Services (ARS). "The purpose of the program is to provide adaptive equipment to assist Arkansans with disabilities in accessing basic telecommunication services," said ARS Commissioner John Wyvill. "The program has primarily served persons who are hearing impaired, but the program was expanded in the 2001 legislative session to include other Arkansans whose disabilities limit their operation of standard telephone equipment."

This means persons with spinal cord disabilities who have limited hand or arm function that would prevent them from independently using a telephone may be able to

obtain adaptations (such as a speaker phone). In order to be eligible for the program, the person must be a resident of the state of Arkansas, meet program financial eligibility (household income under \$50,000 per year), have present phone service in the home and be certified as having an eligible disability.

Once an individual is determined eligible, the TAP staff will assist the individual in determining what equipment is needed and will provide it free of charge. There are TAP demonstration units in ARS offices across the state to assist in selecting equipment.

If you think you may be eligible for this service and are interested in obtaining adaptive telecommunications equipment, contact the TAP staff at **1-800-981-4463** V/TTD or **501-686-9693**.

*Living With Spinal Cord Injury: An Update*, our second miniconference of the year, was held at the J. P. Hammerschmidt Conference Center of North Arkansas Community College in Harrison on October 12, 2001. Over 65 people attended the daylong workshop to hear speakers discuss topics including aging with a spinal cord injury, wheelchair selection, personal training and fitness and new options in bowel and bladder functions. In addition, participants were able to watch mouthstick painters Dale Tabor and Dana Wolf demonstrate their skills. Edgardo Pineda (*pictured above*) of DeQueen was the winner of the drawing for a new Quickie wheelchair donated by Sunrise Medical, Inc.

# Heterotopic Ossification

By Tom Kiser, M.D., ASCC Medical Director

Hetero....What??? I get that response from a lot of my patients and other doctors. Heterotopic Ossification (HO) is a long medical term that describes bone forming in places in the body where it should not be. It is a rare medical condition except when you have a major neurological injury (such as a spinal cord injury or head injury), elective total hip replacement or multiple bone fractures. The reported frequency of occurrence in spinal cord injury is anywhere from 10% to 52%. Fortunately, it causes a problem only about 10% of the time and progresses to fusion of the joint only in 3-5% of individuals.

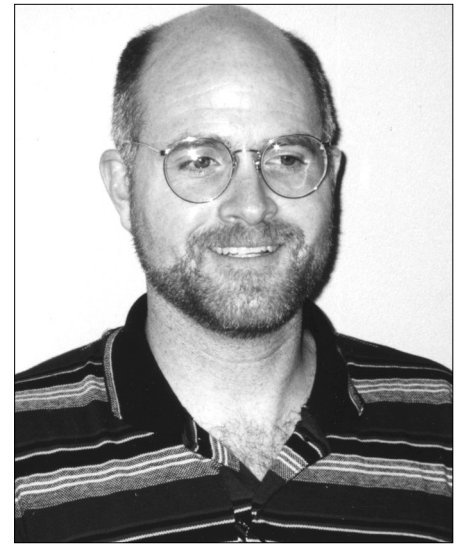
The exact cause of HO is not known, so I will not bore you with the theory. What we see clinically, however, is important to you because you need to recognize the symptoms so you can seek appropriate medical care. HO usually starts with warmth and swelling around a joint, although I have seen a lot of cases where the first sign is loss of range of motion at the affected joint. Hips and shoulders are the most common locations, but it can be seen around the elbows and knees. It starts with inflammation and then bone starts forming around the inflammation and

slowly progresses toward the joint. If no action is taken, the joint can become fused. If the HO involves the hip, that means the person may no longer be able to sit in a wheelchair, because the hip will be fused (or locked) in a bad position.

HO usually develops in the first four to six months after a spinal cord injury, but has been reported to occur as early as 19 days and as late as several years after a spinal cord injury. Often the individual has left the rehabilitation hospital when it first occurs so it is important to recognize what is going on so you can get the appropriate treatment.

Diagnosis of HO is difficult. The bone forms very slowly, so an x-ray will not show the problem in its early stages. A CAT scan or MRI will show the inflammation and the radiologist often thinks it is an infection or an area of bleeding. The best way to diagnose the problem is with a triple-phased bone scan. This is a nuclear medicine study that tells you where new bone is forming.

Treatment focuses on decreasing the inflammation, maintaining range of motion of the joint and



decreasing the amount of bone formation. Non-steroidal anti-inflammatory drugs such as Ibuprofen, Indomethacin or Naproxen are used to decrease inflammation. Physical therapy is conducted to maintain range of motion, and a medication called Etidronate helps prevent calcification of the inflammatory mass. These measures need to be started quickly to prevent the one thing we do not want—bone fusion and loss of joint range of motion.

The important thing from your standpoint is to recognize what is happening and to seek medical care for an appropriate work-up. If we can start treatment early, we can usually slow down the progression of the HO and decrease the risk of future problems.

## ***CAPPS Project Now Available on CD-ROM***

Consumer Action to Prevent Pressure Sores (CAPPS) was a three-year research project funded by the Centers for Disease Control and Prevention and carried out by the Arkansas Spinal Cord Commission (ASCC). The project successfully demonstrated that a group of persons with spinal cord injury who received an in-home prevention education program had fewer and less severe sores than a control group who received no in-home visits. Home health nurses con-

ducted the in-home education program.

The CAPPS Project CD-ROM contains: the Final Report, the Prevention Educator Manual and the Participant Manual. Also included is an independent evaluation of the CAPPS theoretical model used in the project, plus the ASCC Year 2000 Annual Report. The CD also contains a preview of the *Take Control* skin module—an interactive educational tool for the

prevention of pressure sores. The CD is compatible with both Windows and Macintosh computers and is available at no charge to persons with spinal cord injury and health care professionals working in the field of spinal cord injury treatment or pressure sore prevention.

Call Judith Akridge, ASCC Librarian, at **1-501-296-1792** to request a copy free of charge.



## Lifeline Discount Telephone Service

Do you need help getting phone service? Southwestern Bell offers discounts to people who qualify for help with an old unpaid bill, in controlling monthly charges and with phone hook-up charges. Here's how:

You can qualify for special help if:

- (1) your household earns less than \$15,150 a year, or
- (2) you receive federal benefits through Food Stamps, Medicaid (including Supplemental Security Income) or Aid to Families with Dependent Children.

### Help with an old unpaid bill.

If your phone was disconnected because of an unpaid bill, you can take 12 months to pay what you owe, and get phone service re-installed after the first payment.

**Help in controlling monthly charges.** You



have two choices. If you want to make a limited number of calls, choose Lifeline Measured service. For about \$6 a month, you can make 40 free local calls. Additional calls are priced by time of day, distance called and length of call. If you want unlimited local calling and a way to control long distance charges, choose Lifeline Basic service for as little as \$10 a month. This service includes free blocking of long distance and collect calls. Long distance calls can still be made using prepaid calling cards; this gives you built-in control.

### Help with phone hook-up

**charges.** You pay only \$20 for hook-up—half the regular price.

Call Southwestern Bell Telephone at **1-800-472-4087** to apply for Lifeline Discount Telephone Service.

## Spina Bifida Camp 2002

Mark Your Calendar! Spina Bifida Camp is scheduled for **June 23 - 28, 2002!** The Arkansas Spinal Cord Commission, MedCamps of Arkansas, Inc. and Camp Aldersgate, Inc. sponsor the week long camp for ASCC clients ages 6 to 16 at Camp Aldersgate in West Little Rock.

All Campers benefit from this **FREE**, week long experience! The Camp is air-conditioned and fully wheelchair accessible. Campers are supervised by trained counselors, volunteers and MedCamps medical specialists. Activities such as hiking, swimming, fishing, boating, music and crafts are adapted so that each camper can participate to his or her fullest ability.

Applications go out in March, and acceptance will be first-come, first-served, so **get your application in early** to assure your spot at Camp this summer!

## New Year Resolutions

*Continued from page 1*

6. I will do one thing that I usually keep putting off, but should be doing.

### To Be Done Monthly

7. I will get out of my home to go and do something new.
8. I will treat myself to something new that is affordable just because I'm worth it.

### To Be Done Quarterly

9. I will call my Case Manager at ASCC and let him/her know how things are going for me.

### To Be Done Annually

10. I will make and **keep** an appointment to see my SCD doctor for an annual checkup.

Good luck and best wishes for a Happy and Healthy New Year!

## Annie McKnight Retires!

Annie McKnight (*right*) was tickled with her cake at the retirement party given at the ASCC office in Magnolia on September 28, 2001, her last day as ASCC Case Manager. We wish Annie well in her "life of leisure." Janet White has assumed Annie's former caseload. (see related article on page 3).



# Cabin Fever: 105°

by John E. Brasch, M.F.T.

What is the weather like where you are? Is it cold? Snowing? Raining? Sunny? Do you feel trapped inside and just want to break out? Do you feel like screaming out loud because you're going stir-crazy?

When I say the words "cabin fever," what images come to mind? Perhaps you see a woman with screaming kids clinging to her as she looks out the torn screen door of her Texas farmhouse, her dreams as faded as the paint. Or maybe a trapper in Alaska sits confined to the decrepit one-room cabin where he shivers next to a potbelly stove and watches the snow blow in from the cracks in the wall. Perhaps a calendar hangs on his wall as he marks off the long days and prays for an early spring.

So, what is cabin fever? The best answer I could find is that it's associated with being confined in a manner from which you feel there is no escape. (Okay, so that sounds like my entire life!) Do you feel trapped and unable to get out? Do you sense there are no escape routes from your situation? Well, my friend, you may be suffering from cabin fever.

The most common element here is that cabin fever is associated with being *trapped indoors*, for whatever reason—be it too hot, too cold, too wet, too this or too that.

As a wheelchair user, I understand what it's like. I have cabin fever as I write this. It's cold here in Oregon, about 30°, and fog is forecast for the day. Not very hospitable. It will be another day spent mostly inside trying to keep busy, trying not to think that winter hasn't even started yet!

## Signs

I know when my cabin fever is beginning. I find myself rolling aimlessly throughout my home. I open the refrigerator door just to look inside. Perhaps I'll find something that wasn't in there two minutes before.

I also start feeling apprehensive and jittery. I want to go for a roll down by the river, but I can't. It's too wet outside. My chair will get stuck in the mud again. Looks like I'm stuck at home again today.

For many years, "cabin fever" has described the frustrations of feeling trapped inside when you can't get out. As in the example above, it was first applied in the far north where the nights seem to never end while the cold wind blows the silent snow at hurricane force. The wind is so bitter it freezes any exposed skin in a matter of seconds and makes toes and fingers tingle with freezing flesh.

You're trapped inside. You rub the frozen condensation from the inside of the window but see nothing but the blinding darkness of the empty wasteland outside. It has been weeks since you were able to go anywhere. The howling wind relentlessly pounds on the shutters, and all you do is pace the worn-out path on the floor in front of you.

What are some of the symptoms of cabin fever? Some people (including me) report wanting to sleep more than normal, while others say they can't sleep. Many (including me) want to eat more; others don't have the energy to eat.

Cabin fever can create hallucinations and deliria much like a high fever does. It's a real situation and



affects millions of people from all walks of life. Many individuals have no idea what it's like to be in a wheelchair, let alone having to consider the weather elements outdoors. I, for one, am no fan of encountering ice while using my chair. (Does anyone make tire chains for wheelchairs?)

## Solutions

So, what do you do when you feel "trapped?" How can you ease the sensations of being "confined?"

You need to seek what helps you. Below are some ideas with which you can start. But it will be up to *you* to decide what works best.

Don't become discouraged if something doesn't work. You may need to try several things. You may find you like more than you realize. It might take a while and many tries to decide what you like best. Keep trying.

I am a para, and my friend is a quad. We talked about what helps us when we can't get out. We have many differences as to what gets us through the days and nights during the long winter months. Talking helps him a lot more than it does me. Doing things helps me more than him. That's okay. There isn't any right or wrong with what  
*Continued on page 7 - see "Cabin Fever"*

# Cabin Fever

*Continued from page 6*

helps you, with a few exceptions like drinking too much, smoking, drugs . . . Well, you get where I'm going with this.

The most important aspect of dealing with cabin fever is that *you are in control of what goes on in your life*. You are doing this for you as much as I am doing this for me. Such and such activity helps me. What helps you?

Perhaps you like to knit or do needlepoint. I tried this once (only once), but I am too fumble-fingered. Knit one, pearl two looked more like Godzilla tromped through it. But that's okay. It isn't my thing, either. I have the wounds to prove it!

Do you like to play card games? Enjoy music or perhaps just like to sing? Do you write?

My friend likes to read and paint. He is talented, using his mouth to control the brush. He is resourceful, and this, I feel, is the key.

I want to talk about *you* for a moment. I don't know you, but perhaps you have this pressure of feeling homebound, caught up in the sense you might never get out again.

What can you do *right now* to stop this feeling? Can you talk to someone? How about talking to yourself out loud? I do it! (Too much, some say; but hey, it works.) Can you call someone? Or pick up a piece of paper and just draw a few images that describe what you feel?

Put down this magazine for a moment, close your eyes, and take a deep cleansing breath. What will make you feel better and take your mind off the situation? Look around you. What do you see?

Does your environment make you feel comfortable and cozy? If not, why?

I know when I start feeling the effects of cabin fever. I don't really want to do *anything*. I usually have to nudge myself to get started. Otherwise I find myself opening up the refrigerator again every few minutes to see if something new is in there.

A picture titled "Dolphin Journey" hangs above my computer. It helps me take a quick escape from my cabin fever. Just looking at it gives me a sense of peace inside. When I add up all the times I do this escape, I start to realize just how much my minivacations mean to me. When my mind starts to pull me into cabin fever, I break the

thought with a minivacation. What will *you* do when you need a quick escape or a minivacation? Perhaps you'll relive a wonderful experience or picture an exotic paradise.

Remaining active helps me. I listen to music and wave my arms around like a raving lunatic, but this makes me feel good. Isn't that what it's all about—feeling good about ourselves? Not just making it through the day or the next few hours, but about what we do for *us*.

I give you this moment to feel free. It's up to *you* to make it work for a lifetime.

*Copyright 2001, Paralyzed Veterans of America, by permission of PN/Paraplegia News*

## Time to Apply for Education Scholarships!

It's that time of year again—time to start applying for scholarships to fund your higher education.

Each year the Spina Bifida Association of Arkansas and the Spina Bifida Association of America offer scholarships for the next school term. Funds are limited and not everyone that applies will receive a scholarship. Applicants may apply for both the national scholarship and the local scholarship. Requirements and applications differ for each scholarship.

Scholarship applications must be **received by the SBA/AR no later than August 15, 2002**. All local scholarship applicants will be notified by September 1, 2002, if they have been awarded a scholarship or not. If you have received a scholarship in the past you may still apply but priority will be given to those who have not previously been awarded a scholarship.

Applications for the national scholarship must be **postmarked by April 3, 2002**, and submitted to the address on the application. Winners of the national scholarship will be notified by June 1, 2002.

Both applications require different documents to accompany the applications, so *start early* to ensure you have all documents turned in on time. For more details and to receive an application for both scholarships please call the Spina Bifida Association of Arkansas at **501-978-7222** or the National Spina Bifida Association at **202-944-3285**.

The Arkansas Governor's Commission on People with Disabilities scholarships are being offered again this year. The deadline for applications is **March 15, 2002**. For applications and questions you may contact Barry Vuletich at **501-296-1626**.

# New Books in the Resource Center

The McCluer Education and Resource Center on Spinal Cord Injury has added a number of new items to its collection. If you are interested in checking out any of the resources please call the Resource Center at **501-296-1792** or **1-800-459-1517**.

***The Resourceful Caregiver*** (book) was created by family caregivers for family caregivers. It contains over 500 different resources to help caregivers help themselves and their loved ones. Caregiver support organizations, national respite organizations, toll-free numbers for medical transport and many other useful services are detailed in order to help make your life easier.

***Handicapped in Walt Disney World: A Guide for Everyone*** (book) is a guide for handicapped travelers to Walt Disney World. Find accessible and affordable lodging and restaurants, evaluate the accessibility, tips on how to plan your trip and how to get the most out of your vacations are just some of the topics covered in this resource. Experience one of the most famous resorts in the world with the peace of mind that comes with knowledge and planning.

***Taking Charge: Teenagers Talk about Life and Physical Disability*** (book) is based on information gathered during in-depth interviews with teenagers. *Taking Charge*

covers three major areas of concern.

Part One focuses on self-esteem. Part Two explores relationships with family, friends, and the community. Part Three looks toward the future with a discussion of short and long term goals.

***Great American Vacations for Travelers with Disabilities*** (book) is a complete trip planner. It includes essential planning information including local access organizations, wheelchair repair shops, what to pack and tips on getting there. Touring is made easy with information on vehicle lifts.



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